

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 17, NO.3/FALL 2000



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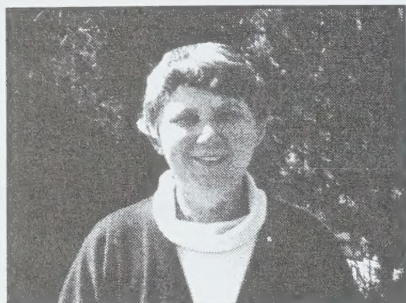
Kari's Skallagrig



Theme for this Issue: AAC Users and Contexts, Then and Now

Character and AAC Users

SHIRLEY McNAUGHTON



Shirley McNaughton

Editor's Note

With this second last issue of *Communicating Together* we are continuing with our retrospective view. This time it is through the eyes of Geb Verburg who has been writing for the magazine since its inception, Nola Millin and Shirley McNaughton. We hope our readers will enjoy looking back over the past seventeen years as much as we have enjoyed searching through the back issues and reflecting on what we had to say in *Communicating Together*.

We apologize for taking so long to produce this issue. As we near the end of *Communicating Together's* publication, many other demands rush in to divert us from our task. We will do our best to ensure you do not have such a long wait for the final issue!

As you will read in Nola's introduction, visual problems have made writing very difficult for her this past fall. We greatly appreciate Nola's contribution, even if in shortened form, to this last issue in which she will participate. We wish Nola much success in overcoming her visual difficulties.

In his review of past articles, Geb reminds us of the goal he has urged us to consider — to which

we have yet to respond as a field — the enabling of children who use AAC to acquire language elements as easily as a speaking infant. He shares his views regarding research, models of service delivery, technology, disability issues, health care and professionalism, among other things. Be prepared, as always for challenging ideas!

Finding Character

Our original plan was for Nola Millin to have half of this issue of *Communicating Together* all to herself, to explore retrospectively past articles relating to AAC users. Nola will explain in her section why she had to take on a smaller portion. While I regret our not being able to publish more of what Nola has to say, I have to admit I appreciate having the opportunity to share some thoughts that are rushing around in my mind these days! This article will serve as my "pensieve" (See Book 4, *Harry Potter*, p. 519). I know I will need another pensieve for my section in our final issue!

Having just celebrated my seventieth birthday, I live in a five-year-old retirement community that presents itself as providing "an adult life style" in response to the current popular dream of a worry-free, responsibility-free, "wellness" retirement. As our numbers grow, there seems to be a gradual realization that there is more than one "adult" life style for seniors. I long for a greater acceptance of diversity and seek to better understand the dynamics of aging. Recently, I was impressed by a CBC radio interview of James Hillman, psychologist and author, as he spoke

about "ageism". I received for Christmas his 1999 publication, "The Force of Character and the Lasting Life", and eagerly looked forward to learning more about Hillman's thoughts on aging. A wonderful surprise awaited me. With the first page, I began making connections between the ideas presented by Hillman, and my personal discoveries about the many AAC users with severe disabilities whom I have known through the years. I decided then and there to take a journey with our readers through the past issues of *Communicating Together*, with James Hillman as our companion. Our destination will be the discovery of "character" and its meaning as we visit AAC users of all ages.

Our trip will not be a chronological one. I have been reminded, in reading the four Harry Potter books that non-predictable events are much more exciting. So our route will lead us as interest dictates. I hope you enjoy our travel together!

Aging, Character and Time

First, I must introduce you to James Hillman's thoughts on aging. He begins by describing aging as "necessary to the human condition, intended by the soul". He entertains the thought that the reason we live so long (past our fertility, our muscular usefulness and sensory acuteness) is that character requires these additional years in order to be confirmed and fulfilled. As someone who majored in psychology prior to my teacher training, I have found it fascinating to discover the thinking of a psychologist with a strong interest in philosophy and history, as he considers aging. Hillman looks beyond physiology, to focus upon *character*, that unique, irreplaceable, whole of each person's nature. He

urges us to move beyond a singular reliance on the ideas from recent research and to widen our perspective through examining how aging is perceived in other cultures and other centuries. (The older one gets, the more satisfying this thought becomes!)

The fixed notion that we are basically physiological creatures and that our thinking about ourselves can be reduced to thinking about our bodies is rejected by Hillman. In its place, he offers *character*, derived from:

kharassein, Greek for “engrave”, “sketch” or “inscribe”; *kharakter*, which is both one who makes sharp incisive marks and the marks made, such as letters in a writing system. “Character” refers to the distinctive qualities of an individual and can also mean a person in a work of fiction or played on the stage. The word wraps together the peculiarities of the author’s individuality, the act of writing, and the book as a stage peopled by imagination. (Hillman, 1999, p. xxv)

In his book, Hillman follows the theme of *character* through three stages: (1) *Lasting* “the desire to last as long as one can”; (2) *Leaving* “changes in body and soul as the capacity to last leaves and character becomes more and more exposed and confirmed”; (3) *Left* “what is left when you have left”. In *Leaving*, Hillman describes how the “dysfunctions of aging convert to functions of character”, and in *Left*, he discusses how “the oddities a person tries to whittle down to conformity during most of his or her life re-emerge in late life to compose the image that is left”.

For the person with severe limitations from birth, the dysfunctions converting to functions of character can begin very early. An attempt to “whittle down oddities” in order to achieve “conformity” would be a fruitless task. The heightening of

individuality (force of character) in AAC users emerges at a young age, and has a lifetime to mature. The two quotations from Hillman that follow epitomize his thesis. They both reinforce the link between character formulation in those who are aging and those with severe congenital or acquired physical impairments. The second excerpt stimulates us as well, to think about a critical difference between AAC users and “the *older ones*” (See italics below).

“Character learns wisdom from the body.” (p. xxix)

Hillman, quoting from and commenting upon DeLillo (1997):

“The work... comes out of all the time a writer wastes. We stand around, look out the window, walk down the hall, come back to the page... “The tortoise determines the pace. We are borne on its back. Exploring as slow thinking, and thinking as slower writing: the *old ones are connoisseurs of lost threads and downtime, because we can’t keep up with usual thought.*” (p. xxv)

It is interesting that the designer of the cover jacket for Hillman’s book chose a tortoise as its emblem. What could be a more fitting symbol for many AAC users as well as many seniors? There are many links between those who are aging and those with disabilities. They are derived from the wisdom that is learned from a body that continuously minimizes what can physically be accomplished, and the quality of character development that comes with extensive time. (There is, however, a major difference that we will discover as we visit Susan Odell’s *character*!)

Through the years, I and many AAC professionals have fought the enemy of time as our students prepared messages, as they learned

new devices, as they mastered the controls of a device or computer, as they attempted to have long conversations with community visitors, as they mastered new skills. Always, the learner lagged behind in output, in spite of huge expenditures of energy and effort. Here, with our focus upon character, time becomes the friend! The AAC user gains a head start on the character formulation that many able-bodied persons must await their senior years to achieve. No wonder I have always treasured my time with AAC users! The force of each individual’s unique character shines forth with every interaction!

It is interesting that Kari Harrington was in her mid-teens when she wrote the two poems that would later be combined to become the lyrics for a song about time. We sing the melody composed by Nancy Gibbons for Kari’s words at every Bliss gathering. The beginning lyrics provide a fitting introduction to the next section.

Take the Time

by Kari A. Harrington

Take the time to look at me
Take the time to listen
Take the time to know me
Take the time to care.
Take the time to ask
some questions
Take the time for answers
Take the time to understand
Take the time to be a friend.



Kari Harrington

AAC Users and Character

Those with severe disabilities must fight against the stereotype of disability held by many members of society. But having acknowledged this, they are free from the stereotypes and conventions imposed upon able-bodied persons. The following excerpts from past articles, either by or about AAC users, aptly demonstrate their force of character, their unique selves. Privileged are we, who can be their friends!

Let's first look at the *Images* left by six AAC users, as celebrated in past issues of *Communicating Together*.

Susan Foster Odell

Changing Attitudes by Susan Odell

I was the first person who communicates with a Blissboard to vacation at Participation Lodge. I was afraid I might not be able to communicate well, but soon found out I didn't have any problems. The aides working there were very good. They took time to talk with me and at night when I was outside they would bring a light so that I could talk. I felt proud because they knew how important that was to me.

Seven years ago I went to a camp where I could use my Blissymbols. I did communicate well at that time, but the staff put me to bed at 10:00 p.m. because they wanted to have some free time. I tried to stop this and told the director about it, which caused trouble for the staff. But things did change there the next year and I enjoyed it more. I think because I caused some trouble, physically handicapped people have been happier there. Other physically handicapped people helped me to change other attitudes at that camp, too.

I am lucky because I have a good hand to talk with on my Blissboard. Some nonspeaking people with

cerebral palsy have difficulty controlling their hands and so have more difficulty making themselves understood.

I hope in the future that non-verbal holidayers won't have difficulty communicating with people. I'm lucky. I have a good mind.

**Communicating Together,
Inaugural Issue, Fall, 1982, p. 10**

Susan Odell: Developing Her Own Voice by Shirley McNaughton

As a speaking person approaching our theme (Developing Our Own Voices), the teacher/parent/grandparent in me focussed immediately on the experiences that are always required for "voice" development to occur and on the contributing role as "experience facilitators" of family, friends and professionals. Susan Odell was very fortunate in having a grandmother and husband, and a wide circle of friends and professionals, who assisted her over the years in the development of her own voice. It was Susan, however, who led the way. She put much energy into expressing what her needs were. Her enthusiasm and her persistence challenged us to make the time and to attempt to provide her with the support she needed. With varying degrees of success, we tried to truly listen to what Susan was saying as her "voice" developed.

Susan participated in a community awareness program throughout Ontario, and in conference presentations and discussion groups in Quebec, Sweden, California, Florida and Pennsylvania. Susan always had two strong messages: (1) cerebral palsy is a physical condition which requires support services for the individual to function at his/her maximum potential; it is not a sickness requiring constant institutional care, and (2) not all persons with cerebral palsy can be helped to the same extent due to

the many levels of involvement associated with this condition. We can, however, do much more to help a broader range of persons, especially those who have communication difficulties.

Susan never withdrew from any opportunity to share her life accomplishments and challenges. She would willingly tell anyone who showed interest about her experiences as the first adult to learn Blissymbols back in 1972 and she delighted in displaying her skill in using this system. She reminisced about her happy and supportive friendship and later marriage with Art Odell, and shared her sense of loss when Art died in 1978. She always sought to inform others of the capabilities of those who use alternative forms of communication and of the importance of having independence and privacy in one's living situation.

A quote from one of Susan's presentations: I feel that, when I communicate, I contribute to the community's knowledge of what it's like to be nonspeaking. Sometimes I feel good that my job gets people to understand our frustration. Sometimes I'm surprised how some people understand and how they aren't frustrated in talking to us. I feel good because I know they understand.

**Communicating Together,
March, 1995, pp. 5-7**

Susan said it loud and clear: "I have a good mind"; "My thoughts are so quick that any technology transmitting them would probably burn out in a very short while!" "When I put my mind to something, I don't stop." And here's the key difference between AAC users and "the old ones" in Hillman's observation above: Both can be slow, but for AAC users, any lost threads and down time can be attributed to the body's restricted movement that

limits the number of exchanges and the speed of expression. For “old ones”, the slower tempo referred to by DeLillo originates with the slower thinking process itself and possibly the slower reception of ideas. The value of the tortoise symbol prevails in both situations, nonetheless!

Next, let's review the sensitive caring *character* of

Andrew Murphy

Helping by Andrew Murphy Age 16: (September, 1984)

People who are permanently “disabled” are generally the ones being helped by others. In each of our lives, however, we all need help from someone at certain times and everyone is capable of helping another person in one way or another. Being able to help a friend gives us a nice feeling. Recently, a good friend of mine, whom I had met as a volunteer at school, had to be admitted to hospital.... When I first went to visit her I felt strange and uncomfortable with the other patients. Then I became used to them and their different ways and forgot about myself and was able to relax and make my friend happy each time I went.... My brothers and sister have a lot of friends who are often over at our house.... I wish they would take the time to learn to communicate directly so that I would be able to answer their questions and ask them questions about what they are doing. This would certainly help me enjoy my time when they are around. And, who knows? Maybe sometime in the future I would be able to help them by being able to communicate with them.

The Future by Andrew Murphy Age 24 (September, 1992)

What does the future hold? Everybody thinks about the future.

We all hope and try to plan for a better life. What that means to each of us will vary. I am no different and spend a lot of time thinking about my future. Thinking about finishing my education so I can get a job. Thinking about developing the skills so I can live on my own, with help of course. Thinking about making new friends and staying in touch with my old friends. Thinking about seeing more of the world and how I can make it a better place..... Last year I successfully completed the fall semester at Edinboro University..... In January, I returned to school looking forward to the challenges of a new year. Unfortunately, my body didn't cooperate. I became tense very often and was biting my mouth so badly that the people at Edinboro were not able to take care of me. I had to return home.

A Tribute from Rev. Gregory at Andrew's Funeral

I have lived a rather fortunate life; my position as a priest and my travels have allowed me to meet all kinds of people who do all kinds of incredible things. And in those moments I am not only awed but challenged and moved to ask deeper questions about my life, my journey, my flight. One of those who stood out for me is Andrew Murphy — for to meet him, to talk with him, to be with him was to recognize that you were in the presence of a man who had done incredible things — but also one who challenged and moved us to ask deeper questions about our own life, our own journey, our own flight. Andrew's journey has come to an end (*at age 26*); too fast, too soon, with so many miles and promises yet to keep. While his sudden death saddens all of us, it is his life, his wonderful life, that stands before

us as a powerful witness of the power of God at work in the world.

A Tribute to a Friend by Kristina Arena

Andrew and I met 14 years ago at his school. Little did I know that the relationship with Andrew, his family and myself would impact on my life so significantly..... He and I quickly became members of the Mutual Admiration Society - mutual admiration for one another in our case. I remember being attracted to Andrew's eyes which seemed to dance when you spoke with him and which followed your every move. He also had a beautiful smile that lit up a room..... Andrew and I had many mutual interests but one of our common interests stood above the rest and this was our love of talking. And talk we did! We had many many talks over the years, and I found his curiosity about the world both endearing and a little intimidating. He had this wonderful knack for asking very direct questions which left me momentarily speechless on more than one occasion.

Before leaving excerpts from *Communicating Together's* tribute to Andrew, I cannot resist including my thoughts regarding Andrew's life challenges and society's response to them, as expressed in 1994. How I wish we could point to many societal accomplishments in intervening years, and that I could judge our governmental policy differently in 2001!

Editorial Comment: Reflecting on Andrew's Life, 1994

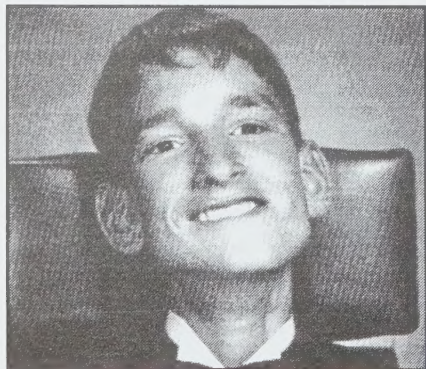
We wish Andrew had had longer to discover where his life would lead. We know he would have accomplished even more! We also know there would have been many disappointments along the road. His last

few months in Toronto, hoping to live in an independent apartment, were filled with frustration for Andrew and his mother and for the other persons waiting to move into the promised apartments with attendant care. Government delays were continuously thwarting their plans.....

The church has been there for Andrew and his family, to celebrate and support Andrew's living. It was there as well, to honour his life and help his family as they grieved their loss. The state, on the other hand, as represented by government policy and institutional attitudes, supported Andrew's existence but gave minimal support to the quality of his life.

The increasing measures of restraint in governmental expenditures are having a profound effect upon the lives of those with severe disabilities. We have a long way to go to ensure that, in the future, young people like Andrew will have the opportunity to participate in the life experiences their accomplishments lead them to expect and we would wish for them. Andrew's writings tell us much about the difficulties he and others with his degree of disability must face and the experiences that can bring joy and balance to their lives. He has given us the knowledge, and hopefully the will, to help others with similar challenges. We will remember!

And we do!



Andrew Murphy

Cam Calfas

Memories of Cam's Friends, shared by Anne O'Malley, 1996

Lynn

... You came into my life and the life of Participation House, 17 years ago. The first time I saw your impish little grin I knew you had character. Just how much I would find out through the years.

We have laughed together, cried together but the most important thing we found out together is that all people have challenges in life and if you find someone to work things through with, most obstacles can be met. You and I found each other..... Cam, if only you knew how much pleasure your painting has brought your family and friends. You always ended up with birds in your work. You told me this meant freedom to you. Well Cam, you're free now. I remember the day you mastered painting musical notes. All you said was, "Wow", but the sparkle in your eye told me the rest.

Roberto

Cam could always make people understand.

Cam helped me inside, to learn to read and in the Bliss class.

He was a friend.

He had family love.

Paul

Cam was a loving man.

Robert

When I moved to PH, I shared a room with a stranger. His name was Cam. Cam and I became friends... He was my best friend!

Val

Cam was my friend. In the morning, he awoke laughing.... I miss his teasing and I miss Cam!

Brian Pamplin

Brian became an AAC user when he was in the advanced stage of multiple sclerosis. He contributed to *Communicating Together* as an associate editor, writing with Alda Steprans, from June 1995 to June 1996. In that short time, his strength of character made a permanent imprint on us all.

Introducing Ourselves

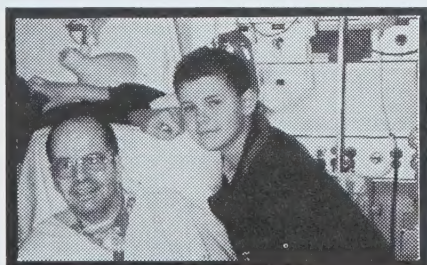
by Brian Pamplin, June 1995

It was a fairly easy transition from home to living in a chronic care hospital because I was becoming a non-contributing family member at home. I found that in a day, I was just getting up, going through the motions of existing and waiting for my wife, Bernice, to come home from work. I felt as though I was doing nothing. My wife was doing a lot of the tasks that I used to do. She was becoming run down. We did get some help when I became more disabled. We used Meals-on-Wheels and I had a caregiver come to the house, but she was only there for two hours a day and she would not give me a shower. she mainly got me up. I had a fully accessible shower and washroom, but she did not want to lift me. I was going to get a lift through a hospital, but I went to a chronic care hospital for respite and decided to stay there.

The hardest part in coming to live at the hospital was leaving my home, but I liked the staff at the hospital. the care I was getting was like the care I would get from family. It was like they were looking after a brother. What I found hard was that I couldn't do simple tasks, like I used to. I physically couldn't do them. That doesn't bother me as much any more. What bothers me the most now is that my son, Gregory, does not listen to me. He does things his own way. It hurts me when he

doesn't take my advice. It could be just him growing up. He's almost ten. In the back of my mind I wonder if it's because I am disabled or in the hospital. I think he's had to grow up a lot in the past year. He's had to, because of changes at home and because of my absence. He's pretty level headed, but it's probably hard for him to deal with my being sick.....

After my hospitalization, Gregory became depressed. None of us picked up on the depression. I feel that if I had been healthy that depression would not have occurred. I did not believe that I could help his depression. I thought that staying in the hospital might help, because he would not have to see me being disabled on a daily basis. I know he thinks of me as a great dad, but he is not used to me being so disabled. I do feel that I am at a disadvantage compared to other dads. I can't pick up the football, like other dads do. My father did not play football with me and my brother and I felt it was an important thing that I had missed in growing up. I wanted to do that with my son. That's why I don't feel badly about my wife's new boyfriend. I feel that he gives my wife and son a lot of things I can't give them. I think that Gregory's depression was due to me coming into the hospital to live. It was the end of the line for Gregory's hopes. He had always hoped that I would get better. I think that Gregory is doing better now. When I recently went home for my birthday, he was very happy. He would not stop kissing me.



Brian Pamplin with his son, Gregory

What do I know?

I'm Just the Patient!

by Brian Pamplin, March, 1996

What does advocacy mean? To me it means speaking up for myself and others regarding mutual and individual concerns.

I find that keeping my thoughts or problems to myself does not work well. It is better to make them known to others. By voicing them, I get to pick other people's brains. I think that is a good thing — because the ideas I have may be off the wall. If they are, hopefully someone will tell me....

I understand why we are called "patients" because "patience" is a required virtue of people who are so dependent on others to help with functions that through most of their lives they took for granted. I don't think I've gotten used to being a squeaky wheel, as I have never been one in the past. But it has been rewarding on several levels. Formerly unaddressed problems begin to be resolved, staff-patient relationships improve, and on a personal level, advocacy helps define who I am.

How the Family Changes

by Brian Pamplin, June, 1996

When I got MS, I told my wife to go and find a boyfriend, and she did. It is better for my son that she did. My son (now eleven years of age) calls him "step dad". I am his "dad". That's how my son differentiates between us. I feel he has been a good influence on my son. If I can't be with Gregory, it is better that somebody else can.

It was important for me to think about and plan for my wife's future. I have been able to see that these changes are made in our family but I have not been able to share all my reasons and my feelings about these

changes with my son and wife.

This is where my communication limitations intensify the difficulties caused by my MS. My wife and son don't realize how much more I would like to say to them.

My family and a few others use the ETRAN when they can't understand my lips, but not many people have the time. The biggest thing is having people take the time.

A Tribute to a Friend

by Alda Steprans, December, 1996

I was just ready to submit my article for this edition of *Communicating Together*, when I learned of Brian Pamplin's death. I needed to go to the funeral home to say goodbye to him, to really understand that he would no longer be there. It was good to see him looking so peaceful, not struggling to breathe or to find a comfortable position, but it still hurts to think that I will not be able to share any more time with him. I will miss that sparkle in his eye and his wonderful sense of humour and understanding. He has left an emptiness in me that I cannot describe, despite the fact that I have so many other wonderful patients and friends that I care about. I feel very fortunate to have known him, to have been inspired by him, to have had the opportunity to learn so much from him. Thank-you Brian!

**by Shirley McNaughton,
December, 1996**

Strange, but when I think of Brian, I think of strength and serenity! Perhaps it was the unexpectedness of discovering these two qualities that made my visits with him so rewarding. It wasn't until Alda was in Latvia last year that I began visiting Brian — initially on behalf of *Communicating Together*, but very

quickly because I enjoyed being with him. From the moment I arrived on my first visit, *Brian made me feel comfortable*. His quiet determination, sense of humour and interest in new ideas, along with his acceptance of the life multiple sclerosis had forced him to lead were evident every time I saw him - even when energy faded quickly- during his months in intensive care. His perseverance when his communication was not understood (both the lip talking and the eye-gaze spelling), the forever twinkle in his eye and the concern for those dear to him, were always there. He was so proud of his son and so caring about the welfare of his wife. I will miss Brian! His courage and generosity of spirit will always be remembered. *Communicating Together* readers have lost an associate editor who had much to teach us all!

Chantal Bedard

Remembering Chantal

by Linda Anderson, June, 1997

Some people come into our lives and touch us in such a way that we are never the same. For me, Chantal was like that. Although I was her teacher, it was she who taught me.

When I first began working with her, she immediately sensed my fear and uncertainty about working with her disabilities. Her own sense of tranquility and patient equanimity calmed me. I was struck with her intelligence reflected in those large liquid eyes of hers, eyes that spoke so much without words, eyes that laughed mischievously and sparkled with shared amusements, eyes that reflected my own soul. Her beautiful eyes too often mirrored the pain of the muscle spasms in her

arms, the chaffing discomforts of her wheelchair, and the frustrations of being unable to communicate verbally. Chantal talked with her eyes. Even without her voice, she was a powerful communicator. Chantal was laughter - who can forget that deep, throaty chuckle which so often rippled through our classroom?

As a student, Chantal impressed me with her lively intelligence, her willingness to work hard and eagerness to learn, her drive to succeed, her ability to organize her work, her patient determination to do well everything she touched.

As a woman, Chantal deeply loved her very special male friend. The special glow in her eyes when his name was mentioned could light up the darkest night. As a woman, Chantal had the hopes and dreams of any young woman who loves....

Chantal was a unique human being. I will remember most her courage, her personal and work ethics, the way she treated people. Everyone loved Chantal. Perhaps it was because Chantal had "personality plus". And she was so much fun to talk to and be with. After she taught me how to use her colour-letter board and Bliss symbols and I felt more comfortable with these, we could communicate well and — she loved to talk! Fashion, music, men, books she had read, life — there was much to discover about her. Chantal made the most of her short life — and lived each day to its fullest.

On earth, a light has gone out and her name was Chantal. In heaven, a bright star shines forever and her name is ... Peace.

by Jorge Almeida

Chantal was my girlfriend. We met at a treatment centre when I was four years old. We went on trips together to Disney World and Toronto. Chantal and I often went together for respite care at the Rotary Home. We were able to talk together without our families. We both used our voice synthesizers..... On September 31, 1995, Chantal went to the Elizabeth Bruyere for respite. There she became very sick and was admitted to the Ottawa General Hospital. On October 4th she was put on a respirator. Later on she went into a coma for six days and caught pneumonia.

I thought I would not be allowed to see her there in the intensive care unit. I thought I would try anyway. I was very surprised when they let me in. I talked to her for an hour and I kept going to see her every Wednesday morning. I would tell her about the news at work. I talked about many things. I felt that she could hear me....

Friday afternoon I went to her wake. I said my last goodbye to her. I went to her funeral on Saturday. I knew her for most of my life. I miss her.

by Treena Guy

I was really proud to know Chantal because she was a fighter in many different ways. I mean Chantal wouldn't give up. If she wanted something she would try to do it. I remember when Chantal was in pain she laughed. I asked her why do you laugh when you have pain. Chantal told me that she didn't want to cry. That was why she laughed.... One important thing about Chantal was that she wanted to find a home for herself because she knew that her parents were getting older. She wrote many letters to politicians and government officials to ask to help

her to get a home. But Chantal didn't get the home she was fighting for before she passed away.

by Justin Clark

I remember once Chantal came to visit me. She was staying at the Rotary Home to give her family time off. The Rotary Home is very close to where I live.

Chantal loved going there but later she couldn't go anymore. It is a relief home for children. There is not any special relief home for adults. It is too bad. Chantal had to go to the hospital to give her parents time off. Jorge had to go to the hospital too. I think that is very bad. I don't know why they did not think about that before.

Martyn Humm

A poem, that expresses the strong impact Martyn Humm's life had upon his brother, was published in June, 1996, a short time before Martyn died.

To My Brother by Nevel Humm

Together we shared a child's world.
We talked, we disagreed,
We shared personal hurts and joys,
And the older we grew,
The stronger the bond between us
became.
I was always so proud to have you as
My brother.

Now Life has taken us down separate Paths,
But your well-being and happiness
Will always be foremost in my thoughts.
Neither the span of miles nor years
Between us can ever change the feelings
I have for you... I love you.

Much of this article has been devoted to those who never reached their senior years. Their *Images*, however, ably demonstrate what Hillman refers to as the final stage of character — "one's remaining image, that unique way of being and doing, left in the minds of others, continuing to act upon them — in anecdote, reminiscence, dream; as exemplar, mentoring voice, ancestor — a potent force working in those with lives left to live." (p. xxx)

Those Building Character Now

In the small space remaining to me, I will turn to those AAC users who are busily *living* their lives and, as Hillman would say, "learning wisdom from their bodies". There are many many examples of their *character* in past issues of *Communicating Together* waiting to be re-captured. Some of their own words have already appeared in their tributes to friends. I have no doubt these unique individuals and many other AAC users will be claiming more space in other venues as they further demonstrate the fulfillment and confirmation of their *character* in the years ahead!

Justin Clark

by Judge Matheson, November, 1982

Communicating Together,
Winter, 1983 and March, 1996

We have recognized a gentle, trusting, believing spirit and very much a thinking human being who has a unique part to play in our compassionate interdependent society.

Kari Harrington

Our Bodies VERSUS Us

by Kari Harrington

Communicating Together, Dec. 1992

Aside from the physical pain it causes, it frustrates me that the

workings of my body have more control over my life than I do. However, I have learned to accept my body and do what I have to, to accommodate it.... If I struggle all the time to try to control it, then that is all I would be able to think about. I wouldn't be able to think about or enjoy the things I *can* do. Controlling my mind is up to me!

Rev. Edwin Lee Mehrlich

Communicating Through Grief... and Love

by Lee Mehrlich, March, 1994

I am my mother's oldest son and I wanted an active part in her funeral. It would be easy for everyone to direct mom's funeral without my input, leaving me on the side of the room alone. And it could have been easy for others to look over the head of someone, like me, in a wheelchair, and while talking to another person, ignore me. Because of my Blissymbolics and Touch Talker™, I was able to have an active part in Mom's funeral....

I have heard that men do not cry. This is not true for me. The thought of Mom not being there for me and the rest of the family was very hard. My pain is still real and so are my tears. They allow me to let out pressure that is bottled up inside me. I feel that my tears show how much I love my mother. I shall not stop them.

Ann Running

Independence of Mind

by Peter Lindsay, Shirley McNaughton, Ann Running & Miriam Running

The body may be constrained but the mind is free.

For examples of independence of mind, that follow this thought by Ann, see *Communicating Together*, Winter, 2000, pp. 5-7

The preceding examples of *character* would not be complete without a reminder of the *character* wisdom of our two associate editors who use AAC. Here is an observation by Nola Millin and a poem by Paul Marshall.

From Nola :

My heart goes out to people with disabilities who are looking for opportunities to contribute to their society. I know what it's like to have the desire to be a part of society but not be able to find the

right place to go. I wish professionals would train children on how to spend their leisure time because one day these children will be adults with free time. You can feel awfully lonely especially if you live alone like I do.... I have experienced meaninglessness and depression. They are not fun things to have gone through but I'm glad I did.... Individuals with or without disabilities need to feel needed and have something to occupy their time. (*Communicating Together*, Sept. 1996, p. 4).

Developing a Voice

To the mountain top:
We must go.
Through the Valleys,
We must walk.
For we are travelers,
On this land.
We will build voices for ourselves.

We will carve out a place to call our home.
It will be carved within us, others will never know,
Until we show the world, the real us.
For years, our voices were silent,
As a student of life.

It's us, Oh world.
Who are you?
Voices from years gone past.
Crushed by the times, lacking understanding
and knowledge.

Born out of silence.
Born are a people, born ready and willing
To be part of the speaking world.
Born to laugh, born to cry.
Born to share with you.

Born to communicate,
We are.

Paul Marshall
Communicating Together
March 1995, p. 8

Character Unchanged

I often think about what has changed or *not* changed over the years in which I have been involved in AAC. In the earliest days of "Bliss", we spent much energy and time drawing attention to the need for persons who were nonspeaking to be admitted to schools, to leave large institutions, to have opportunities for integration, to have volunteer and work experiences, to have AAC systems that allow them to reach their full potential, to have literacy opportunities. On some fronts there have been victories, on others, there remain many challenges. Throughout the years, however, there is no doubt in my mind that the strength of character of those who use AAC systems has not diminished. It shines through in a unique and captivating way for all those who take the time to know AAC users. I hope that by focussing on the force of character within AAC users who have appeared in *Communicating Together* I have been able to heighten our readers' awareness and appreciation of its presence within the AAC users they know, and its timely presence within friends who are aging, as well!

My thanks goes to James Hillman, for giving me a way to describe what I have witnessed for over thirty years — that force of character of those whose souls reveal so much more of their uniqueness than the limitations of their bodies. And thank-you to all my friends who are AAC users, with whom I have learned and enjoyed, so much!

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NOLA MILLIN



Nola Millin

First of all, I would like to thank Shirley McNaughton for her help with this issue. Originally, I had total responsibility to review the consumer input over the past 18 years of *Communicating Together*, but due to four unexpected eye surgeries in a six-month period and other circumstances, I have had to call upon Shirley to help me do some of the reflecting. While Shirley prepares her own reflections, I'm going to reminisce about how I became involved with *Communication Together*. While reminiscing, I'm going to look at some of the articles and issues I have had the privilege to share with readers and I'm going to share how things have, or have not changed through the years. Join me on my walk (okay, "roll") down memory lane.

I first met Shirley McNaughton at a meeting in May of '83 when the International Society for Augmentative and Alternative Communication (ISAAC) was formed. At that meeting Shirley handed out the inaugural copy of *Communicating Together*. At that time, I didn't

give the edition much thought. Also, I thought Shirley seemed like a nice woman but I didn't give her much more thought after those three days at that meeting although I saw Shirley off and on at various functions.

The next time I heard anything about *Communicating Together* was when Ann Kennedy at the ISAAC Conference in Boston, Mass, approached me in 1984. Ann Kennedy asked if I would write an article for *Communicating Together*. My article appeared in the summer 1985 issue. I didn't have further contact with *Communicating Together* until 1991 when Sharing To Learn took over the publication.

Rob Haaf was one of the people who became an associate editor under the editorship of Shirley McNaughton and Peter Lindsay. One of the mandates that this Sharing To Learn group had was to get more AAC users writing articles for the magazine. Rob knew me because I used to visit the treatment centre where he worked. Anyway, I received a call from Rob telling me about *Communicating Together* and the new desire to include AAC users as associate editors. It sounded interesting so I agreed to at least meet with Rob. That decision literally changed my life and has led to many experiences, which are flooding my memory as I write this article. (Besides the fact that I have every issue of *Communicating Together* burying my kitchen table!)

The most significant changes that have happened as a result of becoming an associate editor are the friendships that I have established

with all of the other associate editors. When I started as an associate editor I wrote in the Teaching and Learning section with Rob Haaf and Colleen McGaffey. I had never met Colleen before Rob introduced us. Now Colleen is one of my closest friends. In fact at one point I had to go to London to get another opinion about my eyes and it was Colleen who took me.

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Another friendship that I feel privileged to have developed is one with Shirley and her husband, Bob. Those of you who know Shirley know that she has an enormous heart and is a "mother" to all of us. I have stayed at Shirley and Bob's cottage and I've had the fortune of being able to break the news to Shirley that the bathroom in her new home in Guelph is not as accessible as she hoped. Other friendships have developed with Peter Lindsay, Paul Marshall, and Geb Verburg to name a few. These people have touched my life in many ways and have caused me to develop and grow. It has been Shirley and Peter who have stretched me the most by believing in me and giving me more & more responsibilities within *Communicating Together*.

As I mentioned, I first began as an associate editor by writing in the Teaching & Learning Section. In our first article in the fall issue of 1991, I shared my expectations of a clinician. I said, "As a consumer, I feel that the three most important expectations are sensitivity, practicality and reliability. I want clinicians to be sensitive to my age and specific interests; clinicians should also be practical when providing specified communication devices or services. Finally, I expect the clinician(s) to be reliable in providing the assistance I need in learning and operating a device. Besides the product, I expect to receive training and ongoing follow-up when problems arise. When a therapist meets these expectations, then a genuine process of communication can begin to occur." (Vol. 9, Number 3, September 1991, p. 13) I must say that my expectations have not changed one bit. I still feel these

three expectations have to be present in a good clinician-client relationship.

Rob & Colleen allowed me to write the entire section in the 1991 winter issue where I discussed being integrated. Somehow I managed to only write one Teaching & Learning section in 1992, which was about socialization and independence. I wrote two sections in 1993. The article in the fall issue was about employment/unemployment and the winter article dealt with advocacy and empowerment. It's scary to see the subjects I wrote on during my early years with *Communicating Together* because they are topics that are still very relevant to AAC users today. Not many changes have occurred in these areas.

The June 1993 issue marked a change for me. I wrote the Feature, for the first time, and it was on coping with change. It seems ironic that I'm talking about change in this article as well. This issue represents a big change in my life because this is the last printed publication of *Communicating Together* in which I will have an article. In the future there might be an on-line version of this magazine that I will write for. Anyway, my 1993 Feature article suggested that change is no respecter of persons, it happens to everyone whether it's positive change or negative. I shared that I really believe that in order to accept change positively we need to "talk" about it. It has been almost eight years since writing that article and I will offer people the same advice — share whatever you're feeling with somebody.

Another change occurred in the March 1994 issue. Shirley and Peter courageously turned over the reins of editorship to me. It was the first time that *Communicating*

Together was ever edited by an AAC user. I was hoping to have the entire issue written by consumers. Unfortunately it didn't quite work out but the majority of the submissions were by AAC users. It was truly a thrill and a challenge for me. I must say that both Shirley and Peter were very supportive and were always available to give advice and answer questions. I have to laugh when thinking back on that issue because only a few of the submissions came in through e-mail. I relied on faxes and snail mail. That editing experience led to many more times when Peter and Shirley would call upon my help and ask me to edit or co-edit an issue.

I find it interesting to look over the themes of the issues for which I've had the editorial responsibility. For the March 1994 issue it was "Who Am I?" The consumer/clinician or consumer/parent/clinician relationship was examined in June 1994. "Developing Your Own Voice" was the theme of spring of 1995. I shared an editorial on the topic of advocacy in spring 1996 and shared another on spirituality in the 1997 summer issue. In the fall 1998 issue I wrote about real life after adding my two cents to Peter's spring 1998 editorial. My last editorial was fall 1999 and it dealt with caregivers. Reviewing the themes of the editorials I've written or have helped to write is fascinating because in many ways each editorial, and other articles I've written, have helped to answer that question I posed in my first 1994 editorial when I asked, "Who Am I?" In my editorial on Developing Your Own Voice, I shared the fact that I use a combination of different ways of making myself heard. I still strongly feel that who I am and developing my

voice go hand and hand. Because if I have a voice, whether it's heard or it's seen in written communications, people have a way of getting to know me. Long time readers of *Communicating Together* have gotten to know me and know my "voice" on certain issues. A lot of the topics I have written about tell you who I am. People know I strongly believe in being as independent as possible. Because of my desire for independence, I have been able to write about topics such as advocacy, socialization, employment, and relationships from the heart.

Another section that I have had responsibility for was Yucks & Wows, which itself became a "Yuck" since I didn't get enough submissions to keep the section alive for very long. My favourite Yuck & Wow column appeared in the 1994 winter issue. That column dealt with my computer nightmare; switching from one computer to another one and

getting specialized software to work. Ironically, the speech pathologist I talked about in that column is Tracy Shepherd, who later become an associate editor. I laugh when I think about that column because now computers are an essential part of my life. In fact, my computer was recently hit with a virus and I had to resort to calling Shirley and she had to fax me some information because I couldn't use e-mail. Right there is a major change in all our lives. When I joined the *Communicating Together* group of associate editors, we all would send Peter disks with our submissions, now we just e-mail our stuff to Peter and Shirley.

Remembering that Yuck & Wow column causes me to note that the theme of the December 1997 issue was technology. In my Perspective article I shared my high-tech journey. My closing paragraph states: "So, for me technology has made a huge

difference. The biggest part of this success has been the support I have gotten. As I've said, this support has come from both clinicians and friends. For a number of AAC users technology will probably enhance their lives, like it did mine. It will cause great frustration and even become a nightmare at times, but for me it has been worth it. I wouldn't go back to the days with my electric typewriter and I'll only trade in my computer for a better one. I'm hooked on computers, the Internet, e-mail and all they offer me (including a lot of grief!). My world has indeed opened up because of my computers." (Vol. 14, No. 4, December 1997, p. 23) It is funny to read my thoughts about computers because I'm now pursuing a third degree, which is in Disability Studies, and the majority of courses are done through the Internet.

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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I've been trying to talk about change as I take you down my memory lane. Reviewing some of the topics I have covered in my articles, it's obvious that the issues that AAC users face haven't changed much. I think what has changed for a lot of us is technology. With technology there are more of us consumers who are getting out in society and being pro-active on committees, at social events, and getting involved in issues that affect our lives. Also, technology allows us to communicate with more people, whether it's face-to-face, written word, or through e-mail. In a short lived section called Reflections, which I had responsibility for, the spring 1999 section dealt with

"Communication not Technology." The consensus was that consumers, including myself, feel communication is more important than using the best technology. A lot of us agree that technology enhances our ability to communicate with more people but it's the actual act of communicating that's most important. In my summer 1998 article, I told people how technology allows me to achieve real communication and share what is happening so that when people see me they have an idea of what's going on in my life. So, when we look at change, I feel it's safe to say that in some ways some lives of AAC users have certainly changed. In other ways, we are still facing the same challenges of the

past such as socialization, empowerment, integration, and independence.

Well, that's a look at my past years with *Communicating Together*. I honestly have to say that my life has changed for the better as the years have gone by. I hope that some of the thoughts and feelings I have shared over the years have helped people to see who I am as they see the changes that have happened and that are happening in my life. I hope as well that *Communicating Together* readers will always consider the ongoing process of change in themselves that makes life so interesting for us all.

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Ends and Beginnings

GEB VERBURG



Geb Verburg

Communication, symbols, pictures, and the old self-acquisition issue

I have had fun rereading my old articles and have decided not to republish anything having to do with symbols or pictures. I really have not kept up with that field. I make one exception. I must ask whether symbol users are now, in this new century, capable of transforming a spoken word they hear in their environment, into a symbol on their board, without help. Can they? Because, if symbol users (or any AAC device user) cannot grab a word or concept or image out of their communication surroundings and put it to use for themselves immediately, then nonspeaking children are still at a very serious disadvantage in learning, not just learning language but anything. That has been my pet peeve in AAC ever since the beginning when Bliss and other symbol and picture systems were introduced. And I will try to keep hammering on it until a child with an AAC device can acquire language elements, i.e., words, concepts, ideas, for their own immediate use, as easily, and as

publicly, as a speaking infant.

I would like to share with you again an article written by Christian Aubé. Chris Aubé is a young man, 17 years of age, who attended college for his first year in 1998/9. He uses an AAC device and a powered wheelchair and has great plans for a career in World Wide Web design and development.

From Chris Aubé's

Blissymbolics is an easy word that means a lot. Bliss stands for Beautiful Living Is So Simple — meaning that this method of communication gives a way of expressing their needs to people who are physically disabled therefore getting these people through each day of their life.

When I was a baby I would cry all the time, not being able to express my needs. This all changed one day when a lady introduced Bliss to my parents. They started by putting huge flash cards of Blissymbols on everything in the house so that I would begin to recognize each symbol and realize that by pointing to these symbols I could communicate my needs. When I was old enough to write, I started using an alphabet board and I would spell everything I wanted to say. Then, I progressed to a voice synthesizer, which I presently am using. This is all thanks to Blissymbolics, which enabled me to make people realize that in spite of my disability I too could communicate.

Communication: What is it???

To most people it is a way of expressing themselves verbally. But communication is also non-verbal

even if this way of expressing oneself is not comprehended by many people. When someone has a speech impairment he/she has no other choice but to use an alternative method of communication — Blissymbols, body gestures, sign language, voice synthesizers, etc....

Many alternative methods of communication helped me to express what I needed throughout my life. None of these was my own voice; however, I managed to express myself just the same because people took the time needed to communicate with me no matter which method I used. I cannot imagine what my life would be without having a method of communication. Maybe I would have been in a bed all my life because not being able to communicate might have meant that people would have treated me like a person who was mentally challenged. Maybe the world would be tired of hearing me cry all the time. Instead I graduated from high school and I'm starting college.

The next time you see a person with a handicap using an alternative method of communication, talk with that person. As you will see, those who use any method of communication other than speech are very intelligent people who have something to say. After all, these people were wise enough to learn how to use an alternative method to communicate. Most of these people started communicating using Blissymbols which were invented by Mr. Bliss so that every nation could use the same communication method — solving the main problem which causes most wars, i.e., lack of understanding one another.

Real Independence: a Peek into Part of Chris Aubé's Background

(Geb Verburg)

In 1982 I was part of a study in which two to five-year-old youngsters were given a wheelchair that looked like a Go cart and we called it the MPV (for Miniature Power Vehicle). Christian Aube was one of ten subjects enrolled in that study. He got his cart, was given driving lessons and returned at three month intervals to the centre to be tested both for driving skills but more for changes in physical, perceptual, motor, self help, and academic abilities. The study showed clearly that providing powered mobility at this (for that time early age) was not only possible, it actually enhanced all the measurable skills and many others that we could only assess anecdotally. In contrast to the wisdom of the times the young children who participated in our study were shown to be very capable and responsible drivers and did not damage their parents' homes, their schools, or their siblings. Statistically significant changes in physical motor, perceptual and academic performance were observed, but much more interesting were the anecdotes about participants. One of the subjects learned to use four-point crawl when her cart was not available.

Christian was the source of two memorable anecdotes and I am telling one here as an enhancement and counterpoint to his praise of communication technology. On one of the return visits to the centre, Chris' mother was visibly upset and had a story to tell. The Aubé's lived in Timmins in a suburb. A few days before the appointment, Mrs. Aubé was busy in the house when she received a phone call from her sister-in-law who lived about fifteen minutes from her place. Her sister-

in law asked her where Chris was and she said: "Well, he's in the yard, of course". To which her sister-in-law responded: "No, he's here with his girlfriend". Chris was four-years-old then and had decided to visit his aunt. He had recruited the help of his friend from next door to ring his aunt's doorbell. Chris was in his MPV, his girlfriend was walking and the two managed to negotiate the crossing of several streets (including one large street with a boulevard in the centre) safely, and upon arriving at the aunt's house rang the bell. When the aunt asked Chris: "Where is your Mom?" he said: "Home" or "à la maison". Both his aunt and his mother felt that was a dangerous expedition and that something ought to be done to prevent a recurrence.

When I heard this story I could still sense the emotions on Mrs. Aubé's part. She was in a quandary. Chris loved his cart but could now also use it to do dangerous things. Should she limit his movement or roaming privileges? I pointed out how fantastic I thought the trip had been. Planned and executed flawlessly (as far as we knew), showing all signs of an independent and entrepreneuring pair of children. I felt that it was a wonderful way of learning for Chris and that he obviously had been as careful as necessary to manage to complete the trip safely. Furthermore, he probably would not have been allowed to go alone with his friend if he had asked. I believe that that incident, and the positive interpretation of the "trip", has helped Chris to become more independent. Equally important, it helped his parents to let go of Chris a little more so that he could develop the independence which brought him to the point where he is today.

Thank you, Chris, for helping me learn.

Research or about Cows Mooing Softly

Research also is something that I have written about in four or five issues and this too, I will not repeat here. I think research is doing quite all right. I may not enjoy the topics or find them esoteric or irrelevant but that is the prerogative of the researcher. I, of course still think that groups of people with a strong and broad consumer representation should be involved in setting research priorities. And I continue to have concerns about the level of education and awareness of students that arrive in the field to do their first applied research project.

Medical Model or Models of Service Delivery

The biggest change was perhaps the gradual departure from the traditional medical model, and secondly, the changes in technology at least in children's rehabilitation centres. Nora Rothchild in her retrospective article in the Summer 2000 issue of *Communicating Together*, made reference to the change of the service model, away from the medical diagnosis-oriented model towards one that is family and client based and looks much more at functional abilities. The change in the World Health Organization's International Classification of Impairments, Disabilities and Handicaps (ICIDH2) has already made an impact and will, I hope, continue to do so. The focus on "Human Flourishing" as opposed to health, the introduction of an interactive/social/ecological model of disability rather than a disease or diagnosis-based model are enormously positive changes. Disability is no longer 'a failing of a person'. The environment has been extended well beyond the physical and architectural to include attitudinal, social, cultural, legal, and vocational environments.

ICIDH2 recognizes the role the environment plays in the construction of disability. And finally, the key definitions of disability as “Impairment”, “Activity Limitation”, and “Participation Restriction” allow us much more clearly to point to disabling conditions, situations and attitudes. It is a most beautiful tool for advocacy, made with a lot of Canadian input, and not used nearly enough. (See website addresses later in article, for further information.)

AAC & AT Technology

Another big change has been the evolution of technology from one-off's and prototypes to full lines of commercially available AAC and AT technologies. Assistive device technology has become available throughout the spectrum for almost anything from simple to hi-tech AAC devices. Customers can select from dizzying arrays of mobility and seating technologies (all kinds of seats in all kinds of colours, special cushions, walkers, rollators, standers, wheelchairs, even an upright and stair-climbing one, and scooters) and from new versions of the traditional technology strongholds of orthoses, braces, and prostheses. Service delivery in pediatric (and adult) rehab has arrived at a point where from 85 to 100% of our clients' needs can be met with commercial, off-the-shelf technology. That was certainly not the case 17 or even 10 years ago.

This state of affairs has of course tremendous implications for research and development. Instead of needing to sink money into R&D for new technology gadgets, we can now start to explore means of making sure that people who need the technology actually get it and get the support they need. We can leave the new technology developments to the companies that are making healthy

profits from their current product lines. We can also start looking at how we can help people who use AAC or other assistive technology (AT) to progress into the world of independent living and learning and into the worlds of work and leisure. These are issues that need to be addressed much more extensively than has been done up to now.

Disability Issues

I entered the field of AAC (in 1977) when the term ‘augmentative and alternative communication’ barely existed. When I moved into paediatric rehabilitation in 1980 the term ‘personal computer’ had not yet been coined. Our first Apple II computers arrived in the year of the disabled person, 1981. I knew quite a bit about child development and cognitive psychology (in an academic kind of way) but I knew so little about kids with physical disabilities and their families.

Universities of the 70's did not teach us about what it is like to be a person with a disability. Nor about what is involved in being a parent of a son with Duchene muscular dystrophy. Nor about what it feels like to have a physician tell you that your child has cerebral palsy (earlier the physicians might even have said “CP and probably MR”). I never learned or was told what it is like to have a brother who cannot speak but must use symbols, a word board, or an artificial voice. Nor have I experienced being a parent with a child admitted to the emergency department for a serious acquired brain injury and seeing him come out of critical care, and out of a coma, and out of rehabilitation a changed person — having to mourn the loss of a child as previously known. I was never taught what it is like to have to find the strength to begin the process of building knowledge, behaviour, and confidence all over again in a

son or daughter of 16 or 20. Since I did not know all this, I could not appreciate what parents had been through already and I behaved like “the expert” — that is like “an arrogant ignoramus thinking I knew best”.

I think universities still do not teach that level of understanding. And so the students that come to the paediatric rehabilitation centres still have to learn the most important part of their entire study. Universities still produce graduates who do not know enough about disability issues nor about empowerment, graduates who have no inkling about the role of parents, their child and his/her siblings and their struggles and obstacles.

This lack of understanding or insight can probably never be fully remedied but it can be attenuated in a number of ways. In a 1998/9 article I wrote about stories in the Bloorview MacMillan Centre (BMC) newsletter.

Two members of the BMC Family Advisory Council recently took the initiative to attend orientation sessions for new staff. They felt that they could make suggestions to staff to help make visits to the centre less stressful for parents and families. Some of their suggestions to new staff (and old):

- Smile and introduce yourself;
- Take the time to truly listen to a parent's questions;
- If a parent appears lost or confused, offer to direct them;
- Speak to families the way you would like to be spoken to;
- Show respect by apologizing if you are late for an appointment;
- Put yourself in the family's shoes and try to empathize — “We don't want that pitying look.” “We want empathy”.

These recommendations are hardly earthshaking. Many issues ago I spoke about empowering parents and clients. And even more years ago I wrote about professionals and about ways in which clients and parents could learn to “handle” or collaborate with professionals. We have also addressed attitudes toward clients that left much to be desired. In one way it is nice to see that these topics are now advocated in the Bloorview MacMillan Centre newsletter. On the other hand, it is too bad that it is still necessary to teach new staff how to communicate with clients and parents, including the common civility, not just courtesy, of treating parents and clients as partners, with respect, and with empathy. One would expect that the respective schools or universities would have picked up on that by now.

If you plan to become a professional and intend to work with children who have an activity limitation, or functional or participation restrictions of some kind, I suggest that you spend continuous time in close proximity to a child, young person, or adult with a disability. That usually means living with a family with a child with a disability or at least spending evenings, or afternoons or weekends or a week, vacationing or babysitting with the family or with young adults or mature persons with a disability. In academic circles this may be called “getting to know your subject”. In real life it is called getting to understand a little of what it is like to live with a disability. Not that an able-bodied person will ever really understand what it is like. But perhaps, we can at least avoid those irritating student projects that seem to have only the goal for students to show the world how little they understand of disability issues. Do students need to waste an entire

four-week practicum obtaining “research experience” when they don’t even understand basic disability issues?

Do persons with disability have to suffer the indignity of being exposed to stupid and unthinking questions from naïve and unprepared students? Do we need another questionnaire, developed by students, that purports to assess Quality of Life but does not even ask the person whether they are in pain or whether the assistive device is comfortable? To develop a questionnaire that ignores Maslow’s basic needs, i.e. ignores a person’s sense of comfort, security, and belonging, is a typical outcome of a purely academic exercise. Whoever has worked on such a questionnaire did not have the guts to look at the hurtful issues of disability, did not bother to listen to people; rather they assimilated what they comfortably could, i.e., superficial information.

There are other ways of learning about disability and the issues that are relevant to people with disabilities. We can read books or articles by people with disabilities or watch videos about their growing up (King Gimp is a good example of a short documentary that in 2000 actually won an Oscar in its category). With help from North American rehabilitation professionals I have collected a list of books written by or about people with disabilities.

First, however, a small digression on how I got this list. The question about books written by or about people with disabilities came up on the The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) list. I subscribe to a number of listservs or on-line bulletin boards where people can ask a question or make a

comment and other members of the list answer or respond. The RESNA list is an example of such a list. (For information on how to subscribe, email me —

<gverburg@bloorviewmacmillan.on.ca>).

It has as members many of the most knowledgeable rehabilitation engineers and clinicians of North America, some Europeans and Australians, and possibly people from other continents. Any questions or issues about AT devices submitted to the list will get at least three and sometimes as many as 12 answers or reactions within 24 hours.

The question about “writings by people with disabilities” has been producing a veritable flood of responses recently. I thought I would share a few of these responses while thanking all the contributors to the RESNA list. See the box following this article for a short list of recommended books, web sites and videos. The web site where Shane Wilson, our Marc Garneau Collegiate student, looked for sources and found most of the references is:

<http://www.rehab.state.tx.us/library/wphome.html/>

This web site has an amazing collection of books about rehabilitation, including several of the ones written by people with disabilities. In the process of looking for references, we found the following web sites that provide information about used (second hand) books:

www.abebooks.com
www.bibliofind.com

I go to *Google* (my favourite search engine), type in the name of the book and author, and usually something will pop up, and I go from there.

Finally, an even more important source of knowledge and understanding, and at the same time a testament that independence is becoming a powerful reality, are the web sites and lists that are run by and for, and contributed to by, people with disabilities themselves. I will come back to this later.

Empowerment

In *Communicating Together*, Volume 11-4, 1993, I wrote an article which I will reprint in full here with very small modifications. It was called:

The Ultimate Paradox: Health Care as a Commodity.

Lately I have bumped into an interesting and potentially very disturbing contradiction. On the one hand, we tell people with disabilities that they are empowered and must make their own decisions. On the other hand, health care providers and we (i.e. professionals) continue to believe that it is our job to: “provide care”, “select symbols”, “prescribe AAC devices”, or “be a facilitator in the Alternative and Augmentative Communication process.” That is, on the one hand we are trying to surrender responsibility and on the other we are (I won’t say desperately, but it is definitely) persistently holding on to our traditional role as minor gods and goddesses in the health care field. We keep telling people what to do, how and why. That does not add up. We, health care professionals and researchers, have to make up our minds and decide whether we are for empowerment and independence or whether we want to continue to adhere to the medical model.

Consumers are Responsible for Their Life Decisions

First, let me draw what I think is a logical consequence of the decision to give responsibility to the person with disabilities. You all know that the basis for such a decision is that a person with a disability is not sick, not incompetent and can and should make decisions about their own life, health, and care. They may seek out help or support or advice, but the person with the disability is in charge, is responsible, and is (in very many cases) capable of making those life, health, living, working, transportation, mobility, communication decisions.

Already I can hear the: “Yes, but...”s, “Oh, no!”s or the “No way!”s. Oops, what went wrong? Even the most forward thinking professionals may say: “Yes, consumers with disabilities can be responsible, but ‘not for their communication devices’ or ‘not for their vocabularies’ or ‘not for their mobility devices.’” And that of course is the paradox. We do want consumers with disabilities to be empowered and independent and autonomous – as long as they continue to let us decide the important things like what kind of wheelchair they need, or what kind of AAC device they can really use. That of course doesn’t fly! It is an instance of professionals wanting their cake and eating it at the same time.

Health Care Services as a Commodity

Independence means independence. It means having the right to choose the right AAC device and of necessity also the right to choose the wrong AAC device. It must include the right to

learn from one’s mistakes in the most damaging way possible, which certainly describes a client with a poorly chosen AAC device. Until professionals allow persons to make their own choices, even beyond health care related things such as AAC devices, and wheelchairs, we are not empowering our clients. I believe that this attitude on the part of health care professionals is dishonest both to themselves and to their clients. They are running the risk of keeping their clients dumb and dependent, all for the ostensibly noble reason “we are protecting the client” (from himself or herself). Some professionals will believe, for a little while, that they need to protect their clients. I hope that they too will soon find out that their protection is not helping the clients but is just preserving the traditional role of the professional.

Sought: New Professionalism

We are not protectors of persons with disabilities anymore. We also do not – and if we still do – should not, have a monopoly on control over the health or other life decisions of persons with disabilities. For able-bodied adults, nobody but the person has the right, within ample limits, to decide what to wear, what to ingest, what to drive, what to sit on, what tools or appliances to use or not to use.

Persons with disabilities are dependent on a physician, therapist, or other specialist to choose the chair they sit on, the brace they wear, the switches or joystick they must use, the orthotics or prostheses they must wear. To be dependent for such services upon a physician or specialist is repressive, especially if she or he is the only one in town and may have the

peculiar and unscientific attitude of "not believing in Device X." Such things happen and, in my opinion, are classifiable as forms of soft abuse. They should not happen anymore.

Until every person has the right and opportunity to choose to accept or reject prescriptions, and has an equal right to go to another specialist for a second opinion if he or she so chooses, until that time we are still discriminating against people with disabilities. Only when the service of professionals becomes a commodity, something that persons with disabilities can come and buy without having to surrender all or part of their independence at the gate, only then can we speak of autonomy and independence.

December, 1993, p. 11

Since I wrote that article I think much has changed. In the rehabilitation technology world, many rules, regulations, and practices have been implemented that give consumers more and more say in selecting the devices they end up using. With these new practices comes, I hope, a consequent improvement in independence, empowerment, and device use. I hope that this movement towards rehabilitation service as a commodity will continue and will continue to transfer and add power to the consumers of AAC and AT devices.

Telerehabilitation, Telehealth, and E-Independence

Telerehabilitation

Over the years I have advocated a new model of rehabilitation service delivery almost every other year. So coming back to

models of service delivery is nothing new. As always I ignore whatever I said before and start building a new one from scratch. One of these years I will make enough mental space to incorporate all the bits and pieces into a coherent whole, but until then I will just try to make a small step in the direction in which I think we ought to go.

I would like to make a case for a model of rehabilitation resource services that incorporates different versions of teletechnology in a productive and possibly useful way.

In *Communicating Together*, Volume 14, No. 4, Dec. 1997, I attempted to develop an argument for a system of care in which knowledge about the care (and treatment) of children with disabilities should be actively taught, or at least, freely made available to parents of children with disabilities. This should be provided in addition to and not at the exclusion of a system of properly staffed children's rehabilitation centres. In the back of my head was the idea that it is possible to develop an online information resource, a resource into which one could put relevant and useful information about disabilities, ways to care for children with disabilities, how to get and use devices for communication, therapy, exercise, mobility, positioning, and education online as a gigantic free resource.

If such an information resource or educational system would exist then parents of a child with a disability would be able to learn (or look up) information about the care and nurturing, handling, and positioning their child. Information would be entered by categories such as age level, by different

functional and activity limitations, and by social participation and impairment. Different children would require different support or different levels of support. All this could, can, and I hope will be programmed in an online and readily accessible form. When the children grow up and become teenagers they would start to use the resource by and for themselves and so would become better able to care for themselves.

At the moment, informed consumers with disabilities are, in most cases, the result of many trips to the treatment centres and much more trial and error on their own. The ultimate aim of an information resource for parents of a child, and for persons with disabilities, would be that the expertise about your or your child's care comes to reside with the parents or yourself. And I hope that when I grow old(er) that expertise about elder care will be available for me as an adult with an age problem.

Telehealth

Recently, I heard one of the e-commerce consultants from the Ontario Hospital Association talk about Telehealth, or health over the Internet. He appeared to be most excited about the ability of hospitals to have all the information from all their patients in electronic format. This would allow them to share this information with other hospitals and have it available on a moment's notice to every physician anywhere in the world. Such massive databanks would allow all kinds of research and data mining and we would be able to find correlations between all kind of things. We might find that a history of smoking and

working in a hospital might predispose people to certain conditions. Physicians would then be able to “recall” clients if they were expected to be suffering from such conditions, like a defective car. I was unimpressed with that particularly unimaginative application of teletechnology. It smacked so much of the old medical model that I could hardly believe my ears, but it probably means that the ugly model is not dead yet.

In the same presentation we heard that one of the “disadvantages” of Internet access was that “patients” (those traditionally dumb things that stumble into doctors’ offices), would come into the office with a stack of printouts and would say: “Doctor, I think I have this-and-that”. And, horror of horrors, they would proceed to request a specific medication. Can you imagine? People coming into a doctor’s office with knowledge! With a potential solution to their problem! “Unheard of”, “Unthinkable”, “What has the world come to?”

To me the fact that people are coming to the “expert” with their own hard-won knowledge is one of the most gratifying signs of the power of the Internet and the resourcefulness of people. I hope sincerely that people will continue to be able to find solutions on the web. I only fear that they will soon be able to buy prescriptions without any intervention of a bona fide physician. And one of these days someone will make a mistake and will order and take the wrong medications and the Internet will be blamed. I would rather blame the Ontario Health Association and similar health care organizations for not making sure that people can find on the web reliable and valid information about their medical or social or legal or activity limiting

or participation restricting conditions, so that they can help themselves.

Web sites & online stuff

Some of these online resources are beginning to be developed. A number are being built by people with disabilities for people with disabilities. I found a number of them but have not yet made a thorough search.

I am one of the almost older generation and so I am slow in catching on to the really unbelievable power of the Internet. When I see a younger person sit down and just type in *any question I just asked him or her*, and this weird international brain—this universal memory (just as warped and sometimes kinky as other memories), this library of libraries of scientists and common people—spits out answers, I cannot cease to be amazed. You should try it once, it even beats reading *Communicating Together*! Go for a virtual cruise. Find out what made the Aztecs tick. Figure out which genetically modified grains were in your breakfast cereal. Visit your member of parliament. And always, ... have fun!

Here are the few disability related news and information sites that I have collected:

World Association of Persons with Disabilities Resources or WAPD.

<http://www.wapd.org/links/index.html>

<http://www.icanonline.net/>

<http://www.disabilitytimes.com/>
Disability Times news service

<http://www.newmobility.com/>

<http://rehabcentral.com/>

<http://www.who.int/>
for info about ICIDH2

There are sites that are run or organized by people with disabilities.

A Canadian one is *EnableLink*:
<http://www.enablelink.org/>
“Linking people with disabilities to a world of resources.”

Another Canadian one:
<http://home.nas.net/~galambos/tech.htm>
Disability & Technology: A Resource Collection Compiled by Diane Galambos

A European site:
<http://www.independentliving.org/>

There are so many independent living sites. Here are some more:

Two American sites:
<http://www.cilberkeley.org>
<http://www.ilusa.com>

An Australian site:
<http://members.iinet.net.au/~ilcwa/ilc/>

In Closing

I want to thank Shirley McNaughton, Peter Lindsay and Ann Kennedy—the *Communicating Together* editors through the years—for giving me a soapbox. Most of the time I have enjoyed writing the articles and often they have helped me vent some serious frustrations. Thank you also to the readers for putting up with me.

I want to give the last words to Lew Blancher, and following that, I offer a pot pourrie of interesting reads and watches. I hope you enjoy them as I have.

And now here’s Lew, whose many messages for the so-called “quick and agile” or “quick and empowered” still apply to-day.

Understanding Cerebral Palsy "Accents"

by Lew Blancher (1991)

Like most people with cerebral palsy I was born with my "accent" some 53 years ago. Back then very little, if anything, was known about my physical attributes – athetosis, except the popular diagnosis (or notion) that I would "never learn". But my father, intuitively – or probably more accurately – obdurately knew the assessment to be wrong. He took matters in hand, made me a cage-like walker, and watched as six months later I ran freely around the yard. He saw to it too that, in spite of a long five-year hassle with my detractors, I got into public school and into regular classes. Because of the status quo and events, I had to learn to communicate with the only thing that was available to me . . . my speech.

In an environment that was predominantly quick and agile, my speech was never clear. Only to me was it precise and comprehensible, simply because I knew the message my garbled words were carrying. As a result, my attempts as a youngster to communicate had a Jekyll and Hyde effect on my self-image and emotions. Each new school year, each new neighbourhood I moved into, I dreaded. It meant I had to endure the jeers, sniggers, and mimicry of the others, young and old, all over again. It would take time. It was necessary, to gain the confidence that came with winning a friend or two, and to be accepted as a peer, before I was comfortable and able to communicate effectively. It didn't take too long, however, before even the ones who weren't my friends readily understood me.

The difficulty with strangers and the comparative ease with which I talked with friends had a

confusing impact on me. Being young, and literally not knowing who I was (and trying desperately to know), unsuccessful attempts at communicating would anger me. I'd get very upset with that stupid person standing there, mouth open and eyes blank, who, obviously to me, refused to understand! I expected everyone to be attuned to my messages!

Of course such an attitude on my part is impractical and insensitive, even unrealistic. My defenses in self-respect, no matter how belligerent or retiring, and self-preservation dominated my methods of communication. They (the defenses) got in the way of, not only gaining information and the resulting benefits, but also my growth as a person. It is only in my later years that I have learned a more accommodating approach to the problem.

How to deal with listeners.

When I know that I will be mixing with people who might be unfamiliar with the speech of persons with cerebral palsy, I have in my arsenal a little spiel which I try to rattle off before things get going. It goes like this:

"I know that you may not understand me, but please do not feel guilty or think you are upsetting me. If you will stay with me, I will repeat what I say as many times and in as many ways as necessary. The idea is to communicate!"

There are times, however, when I don't even get a chance to say my little speech. Incredibly, the people I have most problems with, as do many people with disabilities, clear speech or not, are medical professionals.

A Closing Anecdote

Having me deal with medical professionals is like having a dog ask a librarian for a pass card. They look at me and treat me as if I am incapable of talking with authority! Too many times, I've had nurses laugh at me or just plain ignore my existence. A blatant example of this all too prevalent attitude unfolded when I was to have a myelogram done a while ago.

A myelogram is a very dangerous procedure, and because any slip could result in death, a release form has to be signed. A nurse was about to hand me a clipboard with such a form attached when her eyes darkened and her face grew stern. She withdrew the clipboard and turned on her heels. Silly me, I demanded she return. She reluctantly relented and, scowling, watched as I wrote. But when I was settled on the table unable to move, the doctor who was to perform the trick stepped through the door, took one look at me, turned, and asked for someone else to sign the form!

There are historical and sociological phenomena influencing the way we are perceived and treated by others; but direct snubs such as the one described here happen. It is my conviction that it is because we have abdicated for so long our responsibility for our own welfare. That is, we have relinquished the "looking after" of our needs and wants to those who are quick and empowered. Once surrendered, the resulting state of "being looked after" feeds into our (mine and your) inability to communicate verbally and otherwise. We, the persons with the "accent" are still regarded as helpless, incompetent, or mentally deficient. Too many people are still unable to accept us as full and independent partners in communication exchange.

From Geb's Collection of Recommended Books and Web sites

Bauby, J.D. & Leggatt, J. (1997). *The Diving Bell and the Butterfly*. New York: Alfred A. Knopf.

Mr. Bauby had a brainstem stroke, which led to his locked-in syndrome. It's a wonderful little book, both inspiring and heart-breaking.

Hawking, Stephen. (1993). *Black Holes and Baby Universes and Other Essays*. New York: Bantam.

Zola, Irving Kenneth. (1982). *Missing Pieces: A Chronicle of Living with a Disability*. Philadelphia: Temple University Press.

There is a young girl genius who has a form of locked-in syndrome who has an online magazine. Her homesite is at:

<http://atschool.eduweb.co.uk/hojoy/hojoy/hojoy.html>

King, Audrey. (1987). *Lint in Your Bellybutton*. Toronto: Canadian Rehabilitation Council for the Disabled.

A book of clever cartoons.

Beneath The Surface. (2000). Toronto; ISAAC.

A sensitive and reflective book of poems, stories and art created by 51 AAC users from 12 countries.
e-mail: isaac_mail@mail.cepp.org

"When Billy Broke His Head" — a movie on video,
A very insightful and humorous look at traumatic brain injury, made by Billy. Don't miss the ending — It's great! May be difficult to find but it's worth the search!

Dart, Iris Rainer. (1999). *When I Fall in Love*. New York: Morrow.
About a young man with a spinal cord injury plus another character in the book who has cerebral palsy—and all the people in their lives.

Loomer, Alice. (1976). *Famous Flaws*. New York: MacMillan Publishing.
*This book tells the stories of great people who had disabling conditions. I regret that I never reviewed it in **Communicating Together**, for it is such a fun, wicked, and comforting book by an author who experienced disability from many sides. Alice was disabled herself and worked for a large part of her life as a psychologist and counsellor in an adult rehabilitation centre in New York. Alice died in 1998. Until her death we used to exchange e-mails. I miss both her and those e-mail exchanges very much.*

Callahan, John. (1989). *Don't Worry, He Won't Get Far on Foot*. New York: Morrow.

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GEB VERBURG



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